



Breaking down data silos for improved insight

a data transparency perspective

Transparency is all about the release of information by institutions or companies that is relevant for the evaluation of these institutions/companies



openness



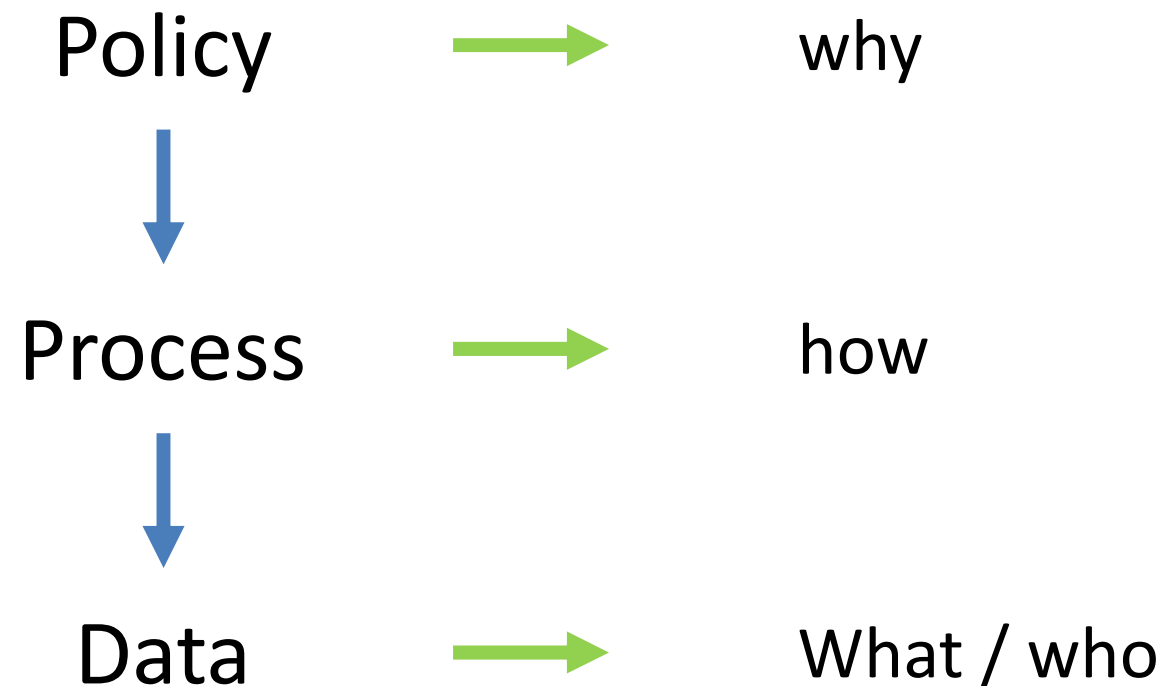
communication



accountability

Trust & Reputation



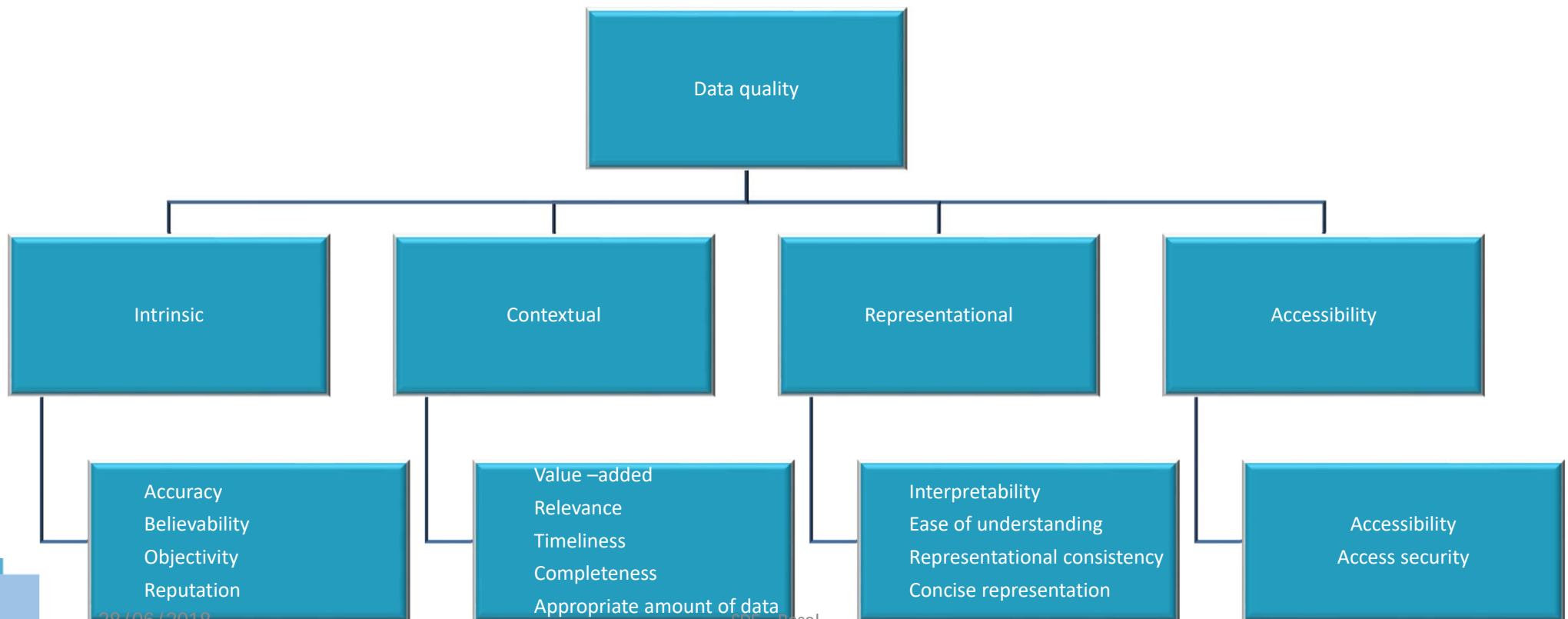


Transparency is all about the **free flow of information** between stakeholders
for the purpose of **informed decision making**

Tacit knowledge  Explicit knowledge



Transparency and Data Quality



28/06/2018

SDE - Basel

Transparency – Benefits and Challenges



Benefits

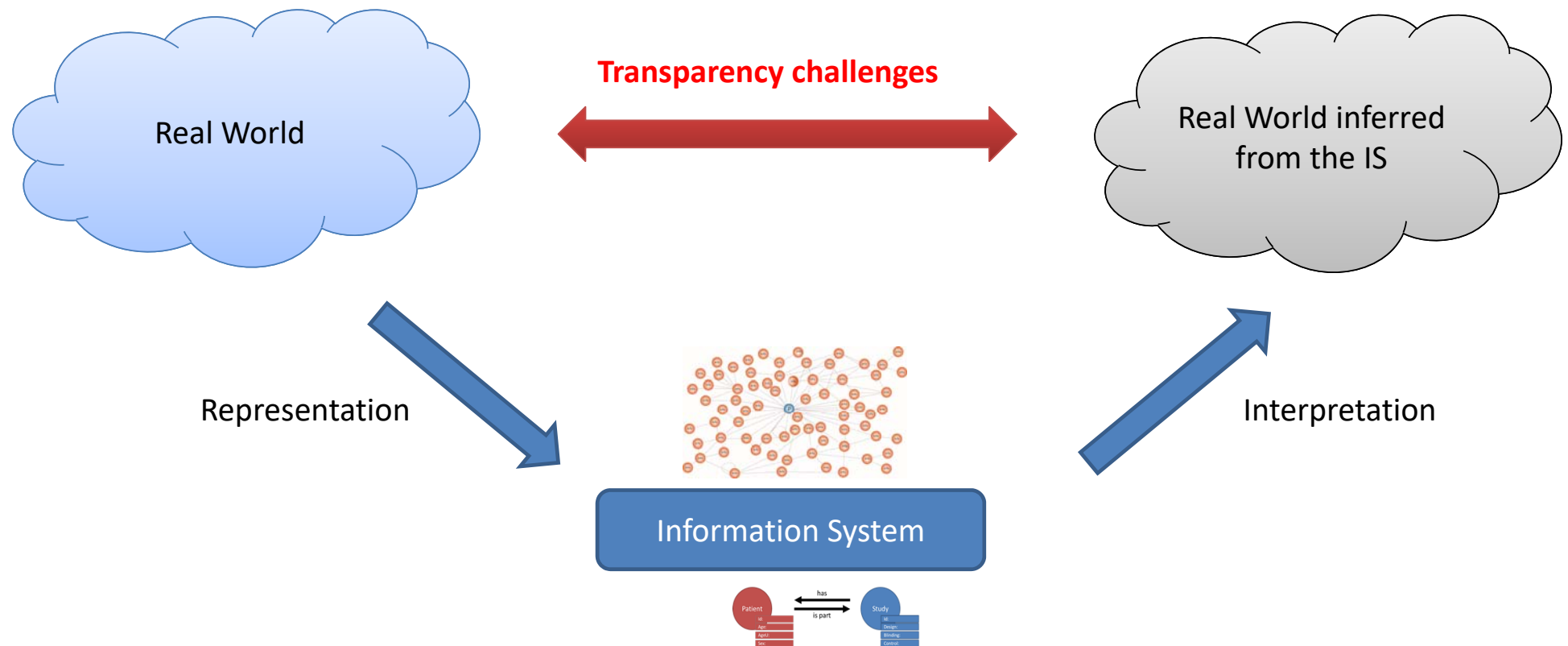
- Autonomy
- Self Control and Motivation
- Accountability
- Feedback

Challenges

- Context
- Privacy
- Security
- Blame culture
- Not a guarantee the right decisions will be made



IT systems as real world representation

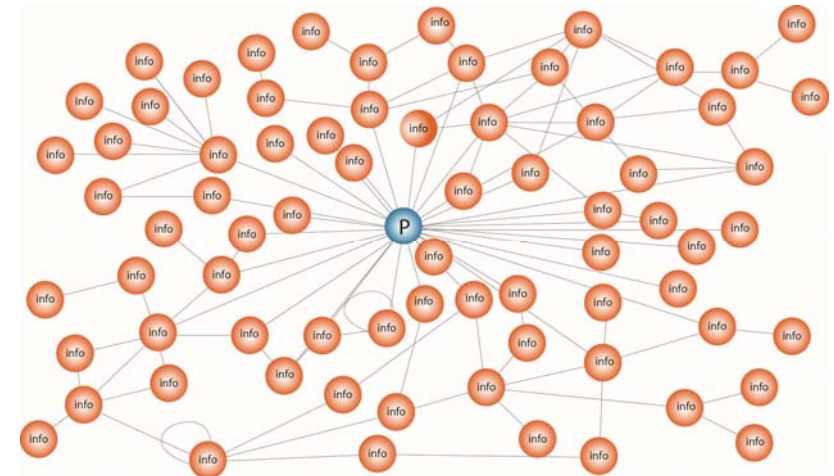


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Formal representation of a knowledge domain, describing its entities, events and processes and the relationships connecting these entities, events and processes

- To share **common understanding** of the structure of information among people or software agents
- To enable **reuse** of domain knowledge
- To make domain assumptions **explicit**
- To **analyse** domain knowledge



“Ontologies” in Life Sciences

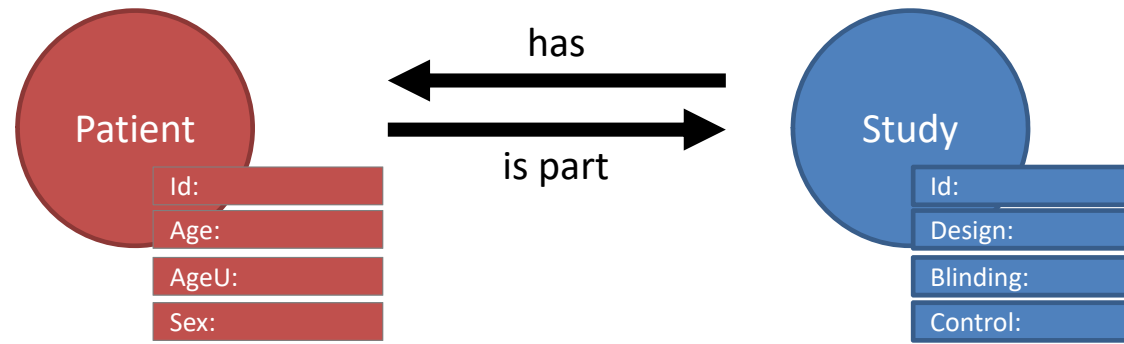


- Snomed CT
- ICD-09/10
- MedDRA

Terminologies – Code lists

Concerned with the meaning of labels
rather than the entity the labels are describing

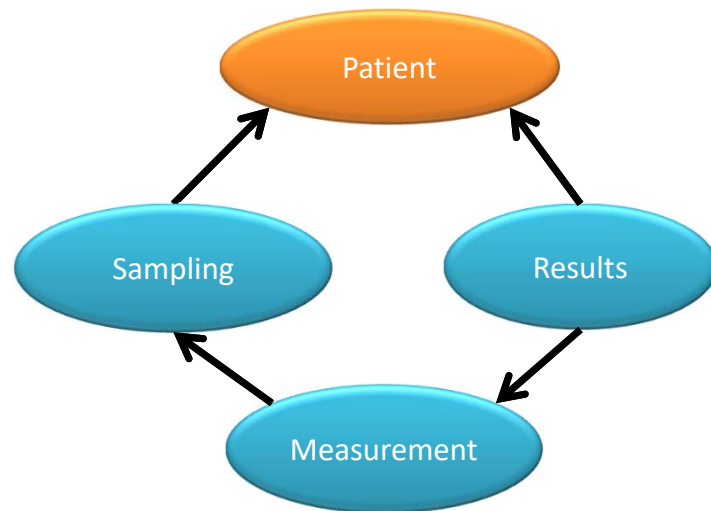




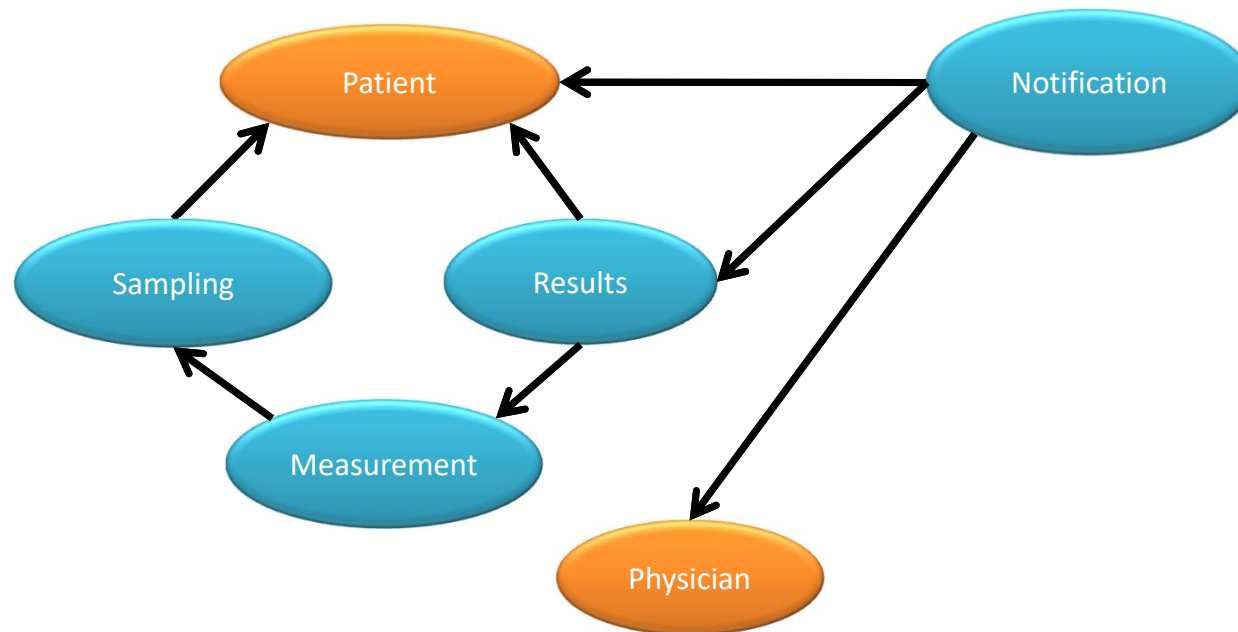
- A concept that can be interpreted by itself
- Classified according to content
- Contains information
 - Fields, groups and attributes
- Contains relations to other Holons
- Each relation has a specific meaning



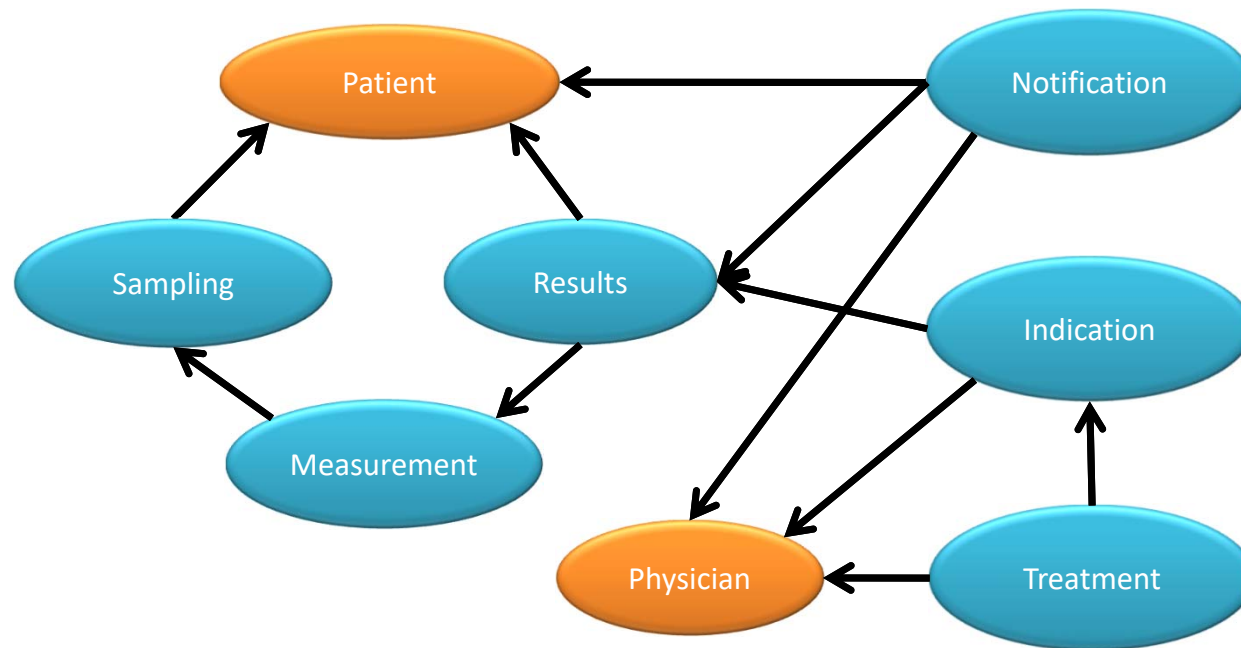
Real World Information Modelling - Using Holons

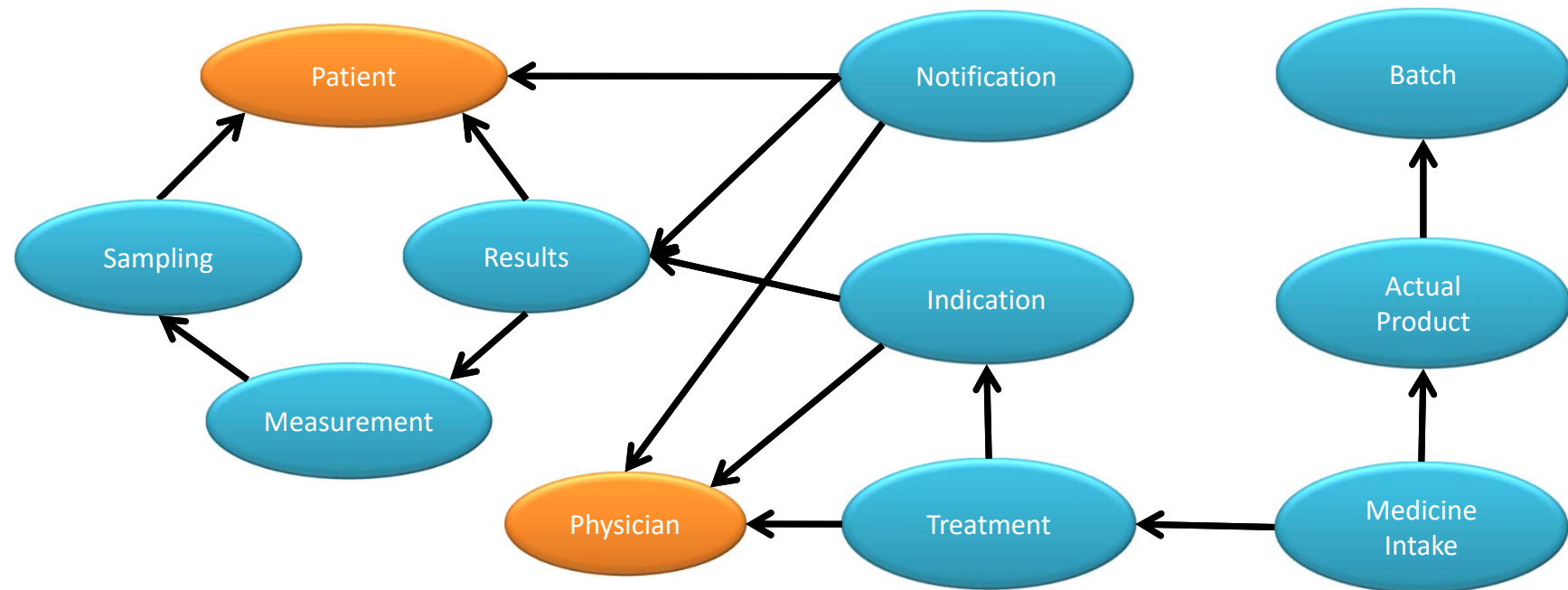


Real World Information Modelling - Using Holons

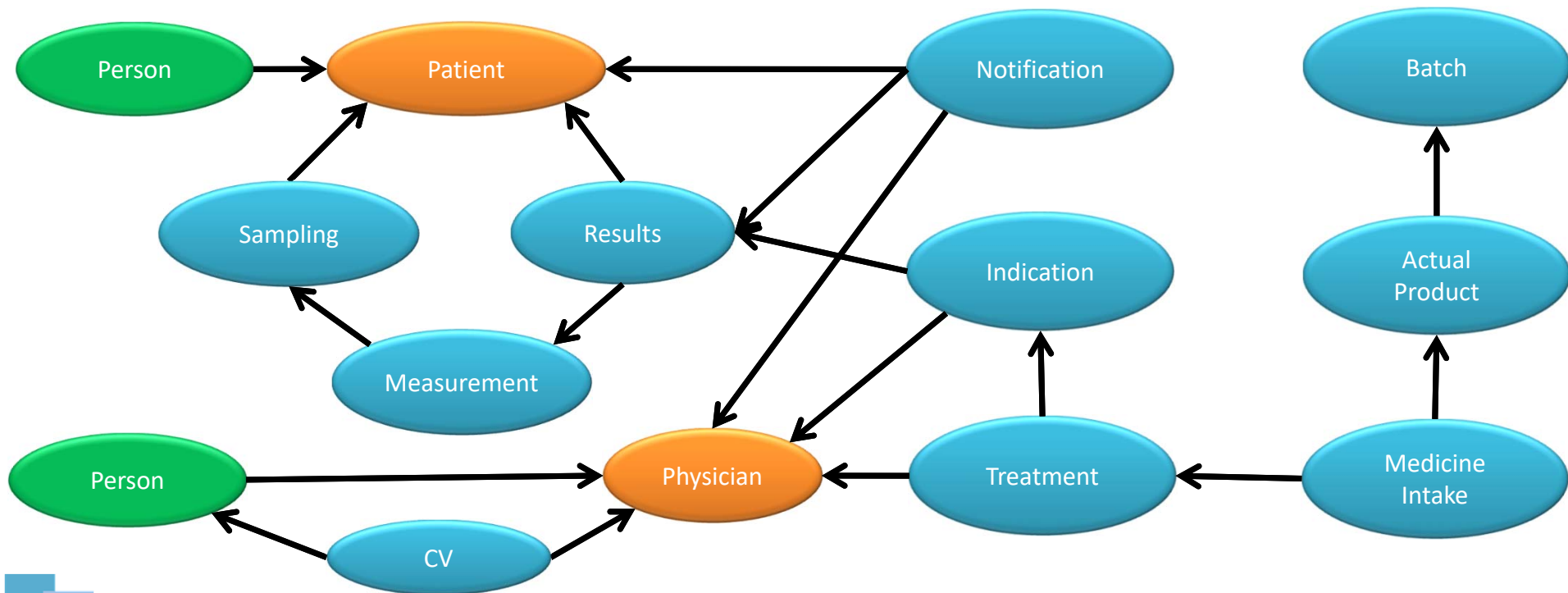


Real World Information Modelling - Using Holons

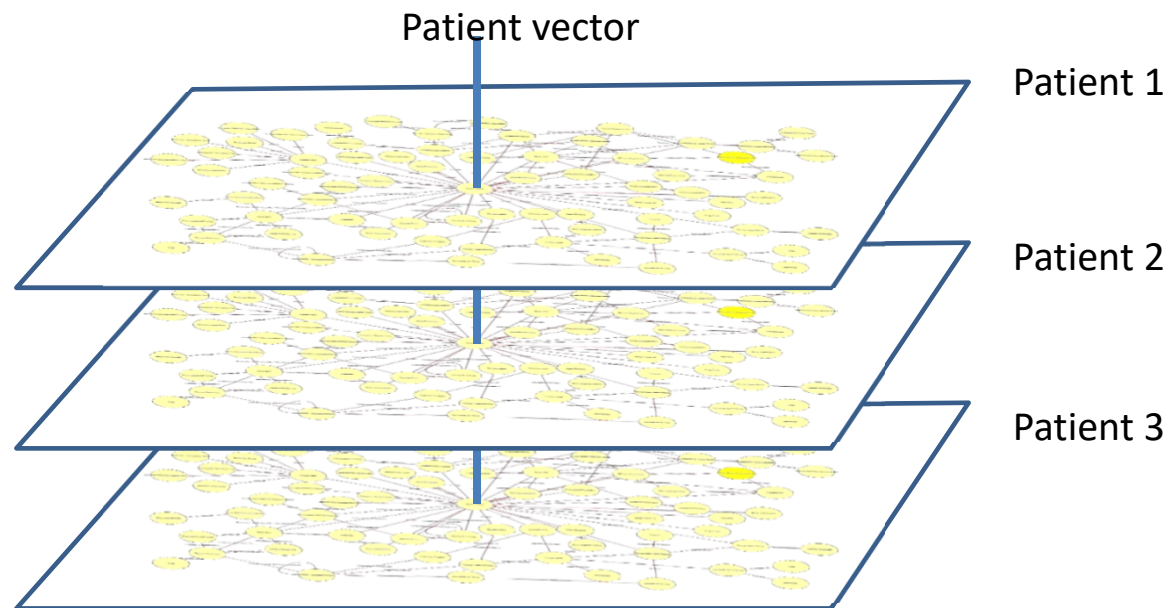




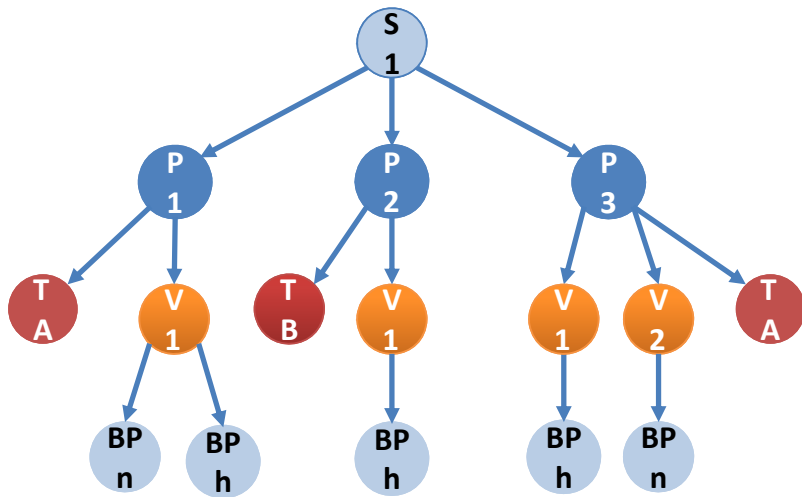
Building a Conceptual “Mind Map” of Related Holons



Ontology vs Instances



Graph database implementation



Holon Graph

- individual nodes (identity index)
- node types (node type identity index)
- property values (property index)
- existence of indirect relationships (relation index)

Select data:

Type of Node: "Patient"

With (Type of Node: "Liver Value", Property: "Value > 5")

Fetch:

Type of Node: "Adverse Event", property: "Name"



Making the most of data collected in a quality registry

COLLABORATION WITH CPUP



CPUP

- a follow-up surveillance program for people with cerebral palsy (CP)
- a National Quality Register (since 2005)
- started in 1994
- a cooperative project between the pediatric orthopedics and child habilitation centers
- prevent the occurrence of hip dislocation and severe contractures by creating a system to survey people with CP in an organized manner throughout childhood.



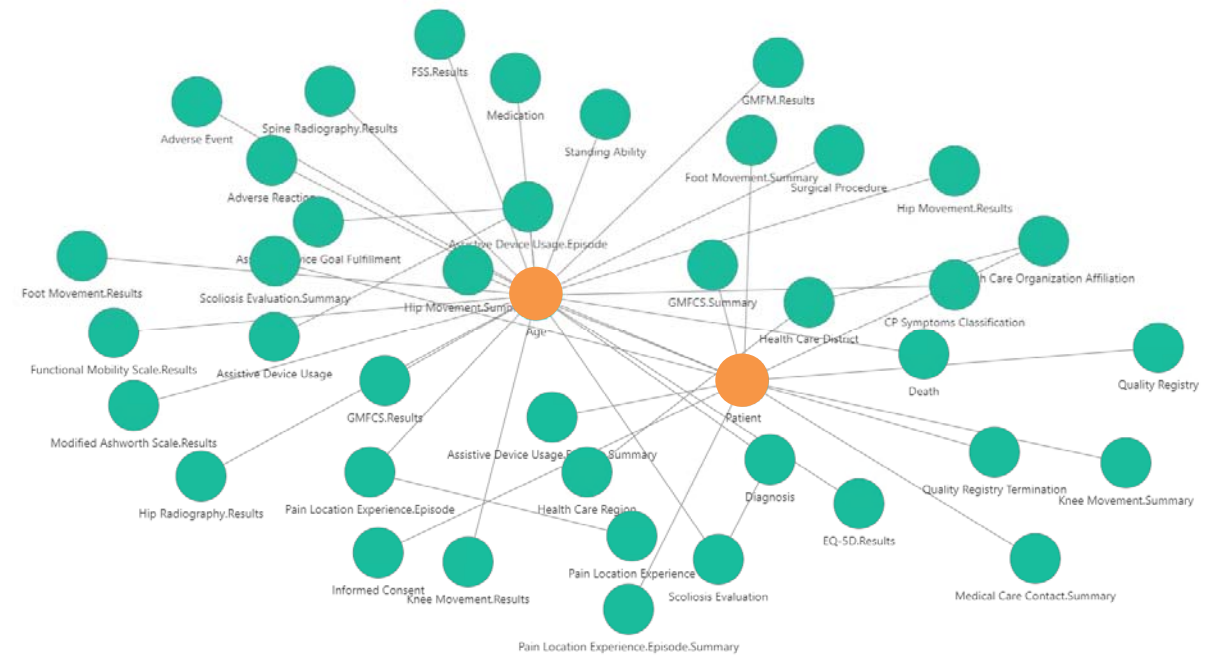
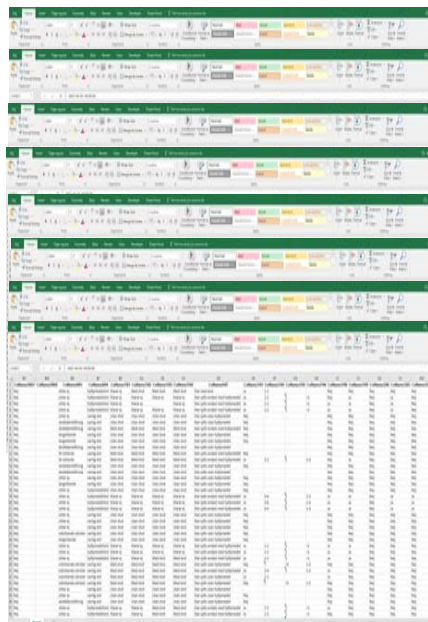
Purpose of Collaboration



- Allow more dynamical interaction and exploration of data by giving researchers direct and better access to data
- Enable longitudinal exploration as opposed to the traditional cross-sectional analysis
- Proof of concept for an enhanced data curation process and software tool aimed at streamlined, intuitive and efficient data exploration. A confirmation that the chosen approach will fill a gap for the health care industry



CPUP ontology



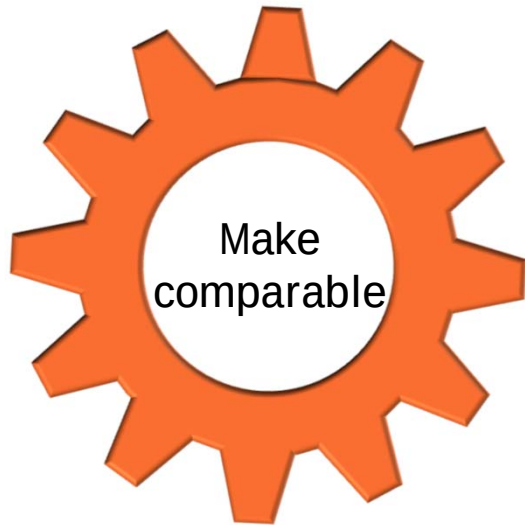
Step 1: Ensure accuracy



Data Quality Control

- Duplicate entries
- Conflicting answers
- Comments in result fields
- Differently spelled values
- Dates

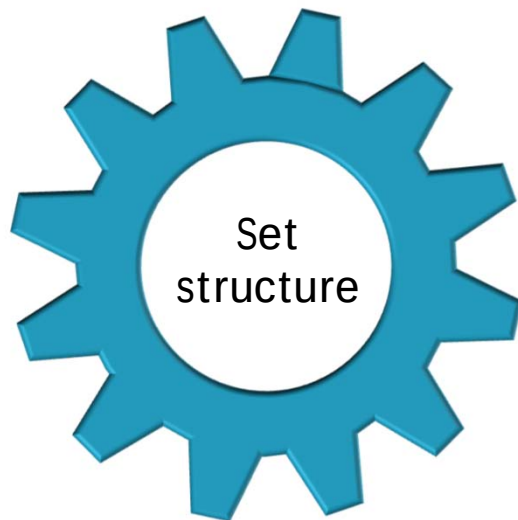
Step 2: Make comparable



Standardization

- Data was
 - standardized to ISO, ICD10 etc.
 - translated to a common language
 - compared to references
- A uniform terminology was used
- Common measurement units were ensured
- Coded values were mapped to understandable terms

Step 3: Set structure



Effective Modelling

- Data was
 - grouped into well-known concepts
 - appended with metadata
- Time was related to events for individual patients
- Episodes were created
- Summaries were created

Modelling examples

Botox yes ☒ no ☐
Muscle relaxant, other yes ☒ no ☐



Medication

Botox
Muscle relaxant, other

Wheelchair Electric outdoor yes ☐ no ☐
Wheelchair manual indoor yes ☐ no ☐
Ankle-Foot Orthosis Left Side yes ☐ no ☐
Ankle-Foot Orthosis Both Sides yes ☐ no ☐
Ankle-Foot orthosis Right Side yes ☐ no ☐
Corset yes ☐ no ☐
Rolling Walker yes ☐ no ☐
Hip Orthosis Left Side yes ☐ no ☐
Hip Orthosis Right Side yes ☐ no ☐
...



Assistive Device

Wheelchair Electric outdoor
Wheelchair manual indoor
Ankle-Foot Orthosis Left Side
Ankle-Foot Orthosis Both Sides
Ankle-Foot orthosis Right Side
Corset
Rolling Walker
Hip Orthosis Left Side
Hip Orthosis Right Side
...



Creation of Episodes



Do you have experienced pain?	Yes	Yes	No	No	Yes	Yes	Yes	Yes
Date	2011-04-01	2011-10-01	2012-04-01	2012-10-01	2013-04-01	2013-10-01	2014-04-01	2014-10-01
Original registrations	X	X			X	X	X	X
Pain location	Knee				Knee			
	-----				-----			
Reported by	Custodian				Patient		Custodian	
	-----				-----		-----	



halsenefvrlängning vd, hamstringsfvrlängning hv.



hälseneförlängning vä, hamstringsförlängning hö.



<b Achilles tendon> <p elongation> <bl left>,
<b m. hamstrings> <p elongation> <bl right>.



Same Tool for Many Uses by Different Users



Capish Reflect Staffan Gestrellius

Available applications

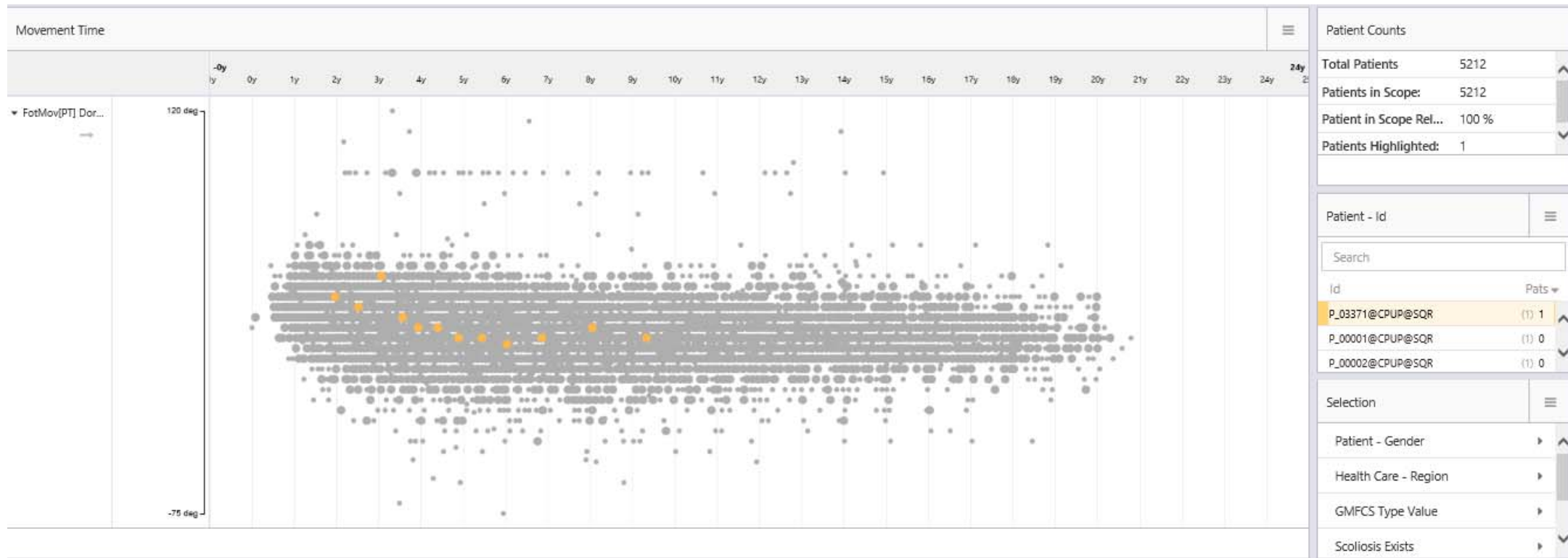
Cerebral Palsy for Surgeons Treatment Follow-Up and Decision Support for Cerebral Palsy Patients. Open	CP Patients for Physiothera... Treatment Planning, Follow-Up and Decision Support for Cerebral Palsy Patients. Open	University Hospital of Lund Personnel Budget Review and Forecasting for Cerebral Palsy Patients. Open	Scania Regional Health Dire... Evaluation of Quantitative and Non-Quantitative Goals in Cerebral Palsy Open
National Board of Health Comparison between Regional Cost Efficiencies for the Treatment of Cerebral Palsy Open	CP for Researchers Comprehensive Cross-Section and Longitudinal Blinded Patient Data for All Cerebral Palsy Cases in Sweden. Open		



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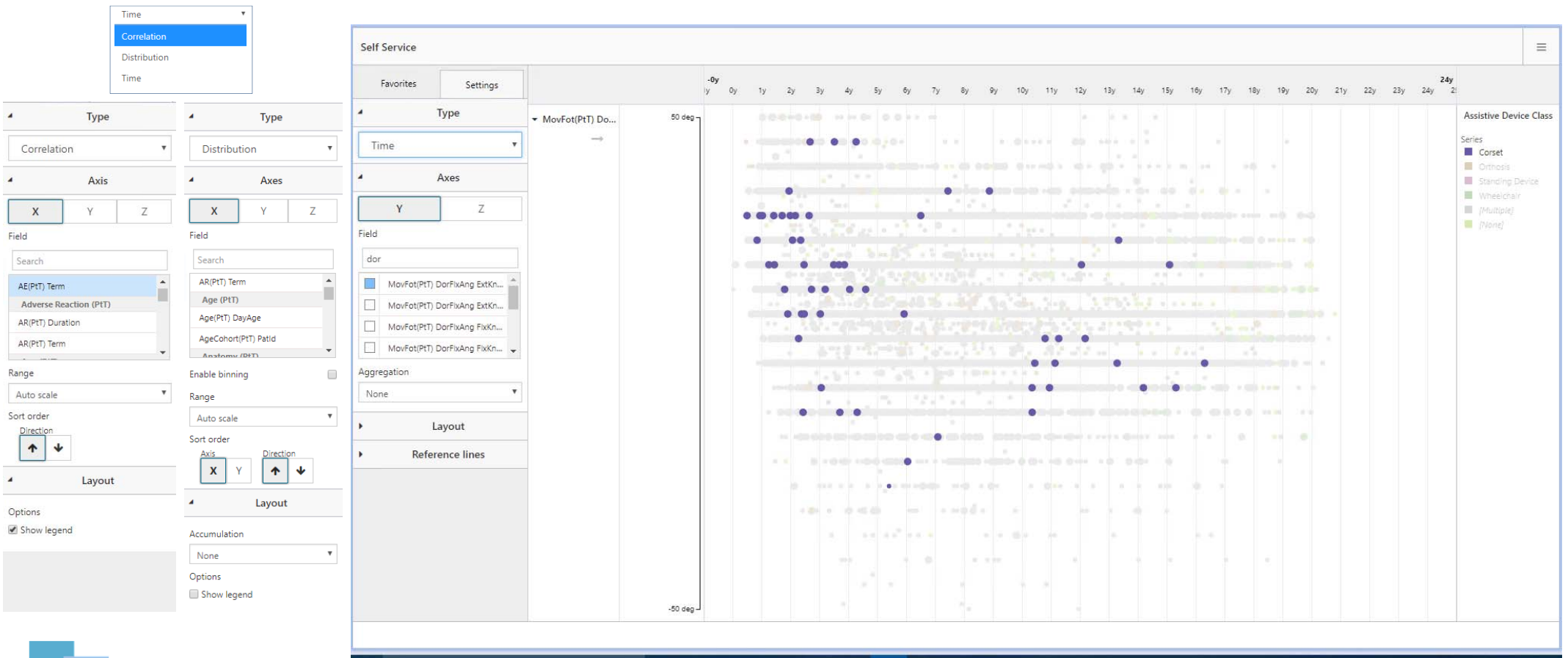
Patient in context – guided analytics



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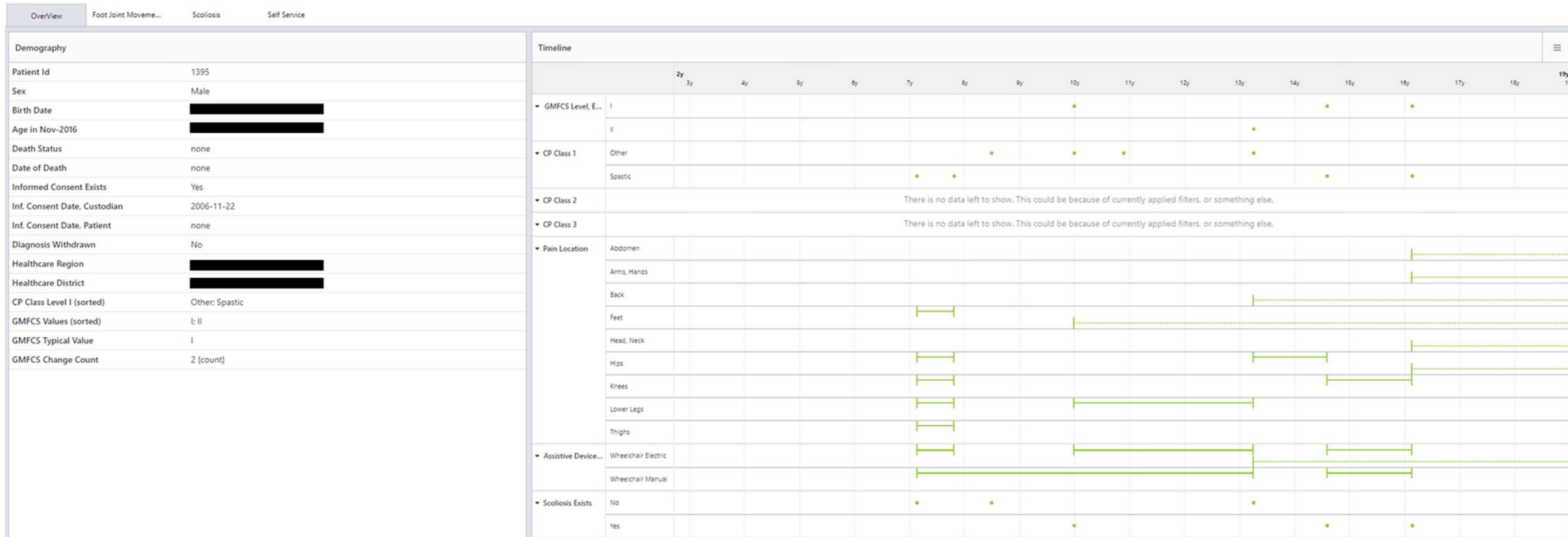
Self Service Exploration



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Individual patient timeline



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Acknowledgements



Capish

- Staffan Gestrelus
- Eva Kelty
- Catharina Dahlbo
- Anna Berg

CPUP

- Gunnar Hägglund
- Ann Alriksson-Schmidt

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